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CLASSMATES MOTIVATE CHILDHOOD CANCER PATIENTS TO PARTICIPATE IN PHYSICAL ACTIVITY DURING TREATMENT: A QUALITATIVE STUDY

Running title: Physical activity during paediatric cancer

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What are the new findings?
<ul style="list-style-type: none">• Psychosocial and professional support is the foremost motivational factor to enhance physical activity during paediatric cancer.• Rehabilitation should start at diagnosis to maintain pre-diagnosis behaviour.

How might this impact clinical practice?
<ul style="list-style-type: none">• Physical exercise and activity should be recommended and promoted.

ABSTRACT

Introduction: Children with cancer experience reduced physical fitness and compromised social relationships during and following intensive treatment. This may negatively impact their quality of life. We explored the motivations to participate in the RESPECT physical activity program during treatment.

Methods: Thirteen semi-structured interviews were conducted with seven males and six females, diagnosed with paediatric cancer in 2013 and treated with chemotherapy (age 8-16 years; time from diagnosis to interview 6-16 months). Interviews were conducted in the children's homes.

Results: The qualitative analysis showed that children's motivations for engaging in the physical activity program during intensive medical treatment were primarily influenced by 1) opportunity for physical activity with a classmate; 2) participation in group training; 3) support from significant others; and 4) improvement of physical wellbeing. Main barriers included 1) poor physical wellbeing; 2) compliance with treatment, medical procedures and being treated in protective isolation; and 3) limited training facilities in the paediatric oncology ward.

Conclusion: Despite barriers, it is possible to motivate and engage children with cancer in daily physical activity during intensive treatment in a paediatric oncology ward. Physical exercise and activity should be recommended and promoted from diagnosis throughout the treatment period including psychosocial and professional support.

INTRODUCTION

Increased understanding of cancer biology, improved surgical techniques and intensified risk group-adapted chemotherapy have led to 5-year overall survival rates above 80% in childhood cancer (Brown, Olsen, Hertz, Carstensen, & Bautz, 1996; Gatta et al., 2009; Smith et al., 2010). However, this improvement comes at a cost. The need to isolate the children for prolonged periods in hospital and at home reduces their interactions with peers and can lead to somatic and psychosocial side effects (Gatta et al., 2009; Gurney et al., 2009; Smith et al., 2010; Lund, Schmiegelow, Rechnitzer, & Johansen 2011). The combination of intensive treatment, side effects and isolation regimens compromises the children's secondary socialization, disrupts social interactions with peers and development of social skills (Giddens 2013). This negatively impacts the children's health-related quality of life (Gurney et al., 2009; Mitby et al., 2003; DuHamel, Redd, & Wickberg, 1999). Moreover, their physical fitness levels diminish (Braam et al., 2016) due to sedentary lifestyles imposed by the treatment and lack of physical activity (Brown et al., 1996; Oeffinger et al., 2006; Braam et al., 2016). The challenges mentioned above may be alleviated by physical exercise. Few studies have addressed physical activity in children with cancer. Most studies have small sample sizes and describe various exercise interventions, outcome measurements, and duration of interventions (Braam et al., 2016; Winter, Muller, Hoffmann, Boos, & Rosenbaum 2010; Huang & Ness, 2011; Grimshaw, Taylor, & Schields, 2016). Overall, the studies indicate that children with cancer are less physically active and have decreased muscle strength, balance, and cardiorespiratory fitness during and after treatment compared with their peers (Braam et al., 2016; Winter et al., 2010; Huang & Ness, 2011; Grimshaw et al., 2016). Moreover, a long-term decline in physical fitness can lead to metabolic disease (Oeffinger et al., 2006; Jones et al., 2014); however, this can be moderated by physical activity (Oeffinger et al., 2006; Tai et al., 2012). The few physical intervention studies conducted in children with cancer during treatment show that physical fitness can be improved (Braam et al., 2016; Winter et al., 2010; Huang & Ness, 2011; Grimshaw et al., 2016). A few studies have examined barriers and motivations for children with cancer to participate in physical activity during treatment. The studies indicated that improvements in physical fitness and mental well-being, health counselling and accessibility to physical activity facilities, and fun and sense of self-efficacy were main motivational factors to participate in physical exercise (Götte, Kesting, Winter, Rosenbaum, & Boos, 2014; Keats, Culos-Reed, Courneya, McBride, 2007; Barakat, Galtieri, Szalda, Schwartz, 2016). However, the varying frequency and compliance with physical activity and the small part of participants attending the programs suggest a further need for exploration of motivational factors for engaging in

physical activity during treatment. Barriers includes physical, psychological, and organizational aspects such as lack of awareness on physical activity (e.g. children, parents, physicians), oncology treatments and associated physical changes and side effects (e.g. nausea, fatigue, dizziness, pain), social isolation, feeling of weakness and experiencing decreased pleasure, and overall lack of energy and motivation ((Götte et al., 2014; Hartman et al., 2009; Keats et al., 2007; Barakat et al., 2016). Parents' behaviour related to physical activities of their children differs between being supportive, inhibiting, and inert and only a few patients receive information about exercise during treatment by their physicians ((Götte et al., 2014). Decreased and impaired physical capacity and function lead to problems with balance and dynamic movements like running and jumping, which could be considered as everyday activity in children. The pronounced decline in physical strength and function constitutes a possible safety issue when performing exercise during childhood cancer treatment, due to the risk of falls, injuries and pain. Exercise interventions seem to be beneficial for children and adolescents with cancer, however positive effect will never happen, if children are not motivated to be physically active. It has been shown that adherence matters to outcomes (Hartman et al., 2009). In this study, we wanted to evaluate the motivations and barriers in the presence of a structured and daily conducted exercise program, tailored to each child's needs involving professional and psychosocial support.

METHODS

Participants

Criteria for RESPECT eligibility were: age 6-18 years; diagnosed with cancer, Langerhans cell histiocytosis or myelodysplastic syndrome; treated with chemotherapy at a paediatric oncology unit in Denmark; enrolled in school at the time of diagnosis; and able to communicate in Danish. Exclusion criteria were limited to mental disability (for example Down's syndrome) or severe co-morbidity.

Thirteen of the first 21 children entering the RESPECT study from January to October 2013 were selected by the purposeful sampling strategy; maximum variation sampling. This method uses maximum variation to ensure heterogeneity in order to better understand how the phenomenon under study is perceived and understood by different children at different times (Tables 1a and 1b). Variation was attained and adequate based on age (median 12 years, range 8-16), sex (seven males and six females) and diagnosis when we had included 21 children. The median time from diagnosis to interview was 9 months (range 6-16), ensuring that the children had sufficient experience engaging in physical activity during intensive treatment. Ten of the children were still undergoing treatment and three children had just completed treatment.

Table 1a shows the characteristics of the intervention cohort and interview information. Data on cancer diagnosis and date of diagnosis were collected from medical records. Table 1b shows the levels of participation in the training scheme and physical activity pre-diagnosis collected at diagnosis.

Intervention design

The RESPECT study (Rehabilitation including Social and Physical activity and Education in Children and Teenagers with Cancer) (Thorsteinsson et al., 2013) is an integrated part of CIRE (Centre of Integrated REhabilitation of cancer patients), which is a research centre established and supported by the Danish Cancer Society and The Novo Nordisk Foundation aiming at exploring how intervention strategies, including physical activity, influence rehabilitation of children and adults with cancer.

The RESPECT study is an ongoing nationwide population-based prospective, controlled, mixed-methods intervention study. The intervention program was conducted by trained sports psychology consultant TT (first author, M.Sc.) in the paediatric oncology ward. The children with cancer were

activated and motivated to be physically and socially active during treatment by professional and psychosocial support. The in-hospital intervention, from the time of diagnosis and throughout the treatment period, combined daily participation in supervised individual physical activity and group-based physical activities twice weekly with other children and their ambassadors. As part of the RESPECT study, each hospitalized child had two healthy classmates assigned as ambassadors. The ambassadors visited the child with cancer at the hospital (9 a.m.to 3 p.m.) at alternating two-week intervals and participated in the intervention program. The daily supervised physical activity sessions were tailored to each child's needs, gender, age, side effects, capabilities, level of activity pre-diagnosis (self-reported by questionnaire), and support from their social network. Training sessions of 5-60 minutes were carried out three to five days weekly during hospitalization. The duration of each session depended on the overall and daily well-being of each child. Individualized sessions took place in various settings, for example in the child's hospital room, in the hallways of the paediatric oncology ward or elsewhere at or nearby the hospital. The twice weekly group training sessions included all admitted and eligible children and their ambassadors and took place in the hospital's physiotherapy facility, the paediatric oncology ward's common area or outside the hospital. Activity sessions focused on physical functionality and balance, muscle strength and cardio-respiratory fitness during treatment. Supplementary file 1 outlines some of the most common exercises used in this intervention. Social and mental skills training were performed when the child with cancer was not able to perform physical exercise as well as during exercise sessions and social sessions.

Interviews

All interviews were conducted in each child's home from February to May 2014 by TT using a semi-structured interview guide. The semi-structured interview guide was developed exploring the themes: physical activity during treatment; individual and group-based training sessions; physiological tests; motivational factors for engaging in physical activity; and influence of professionals, ambassadors, parents and other children with cancer. The children were repeatedly encouraged to reflect on both positive and negative aspects. The interview guide contained open-ended and indirect questions and we phrased our questions to show its okay to answer in a way that was not socially desirable (e.g.; what did some of the other children think about a particular situation?). Other examples from the interview guide; 'How did you experience the training sessions? Do you have any concrete examples? Tell me more? What are your thoughts on this experience you're going through right now? Who told you to do exercise? Tell me about the ambassadors?

Thirteen semi-structured individual interviews were conducted. Interviews took 25-90 minutes (mean: 44 minutes). Data saturation, defined as no additional themes addressed by the children, was achieved following the sixth interview. We discussed our findings with the children involved and asked them to judge the credibility of the results. The recorded interviews were transcribed verbatim and imported into the computer software program QSR NVivo 10 (NVivo qualitative analysis software 2012) for processing. The qualitative data analysis strategy systematic text condensation (STC) was carried out in accordance with a four-step analysis procedure described by Malterud (Malterud, 2012). STC, inspired by phenomenological ideas, is a descriptive pragmatic approach, presenting the experience of the participants as expressed by themselves and implies analytic reduction with specified shifts between de-contextualization and re-contextualization of data (Malterud, 2012). The first step involved reading each child's responses in order to get an overall impression of that child's narrative. The second step identified meaningful units (qualities) by extracting phrases or sentences about the children's experiences with the intervention. Step three involved abstraction of individual meaningful unit content by capturing them in different dimensions (Malterud, 2012). Finally, the importance of these dimensions was summarized and sorted by category. Each statement given by the children was coded independently by two researchers (TT and HBL) and then compared and discussed involving another researcher (LHL).

Methodological considerations

The qualitative method used in this study (STC) provided an analysis of motivational factors that engage children in physical activity during treatment. We thoroughly elaborated a study question and a thoughtful purposive sample strategy, allowing us an overview and a contextual adhesion. Conducted with stepwise data collection, recruitment, and analysis, a feasible and limited amount of data and participants were needed for responsible analysis with STC (Malterud, 2012). We applied Malterud's guidelines for authors and reviewers of qualitative studies (Malterud, 2001). The credibility of our study seems high as we have established factors that may predict children's motivation to engage in physical activity during childhood cancer treatment. To ensure credibility we discussed our findings with the children involved and asked them to judge the results. They recognized and accepted the findings. To ensure transferability, we have thoroughly described the research context and the assumptions central to the research. Data saturation appeared early in the interview process, supporting the fact that the children had similar experiences. This suggests that transferability and generalizability of the present study are likely to be high. As mentioned, we

applied STC described by Malterud (Malterud, 2012), involving an overall impression of the child's narrative, identifying meaningful units (qualities), abstraction of individual meaningful unit content by capturing them in different dimensions and finally summarizing and sorting them by category. To confirm our results and ensure dependability each statement given by the children was coded independently by two researchers (TT and HBL) and then discussed and compared involving another researcher (LHL). Results should therefore be transferrable to similar contexts and settings relating to rehabilitation of hospitalized children burdened by long-term serious illnesses. The simple and rigid procedures of STC are accessible and give limited space for creative interpretations and conclusions (Malterud, 2012).

The strengths of the current study are that all training sessions were conducted by the same person who was in the ward daily and had daily interactions with each child, promoting them to be physically active. This ensures that the intervention and the applied approach were consistent and based on similar principles and methodical approach. It may be considered a study limitation that the same person conducted the interviews and was responsible for the physical training sessions. This could constitute a social desirability bias, which may have influenced their answers. However, it is our impression that the children were able to engage in honest and direct communication since interactions and this explicit form of communication have been practiced daily and the children were repeatedly encouraged to reflect on both positive and negative aspects. In developing the interview guide we phrased questions to show its okay to answer in a way that was not socially desirable (Weber, Miracle, Skehan, 1994; Sacks & Westwood, 2003). To further meet this limitation, we involved and discussed our findings thoroughly with other researches and asked the parents if they could recognize our findings. Indirect questioning were also used for socially sensitive questions to allow the children to project their own feelings onto others and still provide honest, representative answers. To minimize confirmation bias, we continually re-evaluated the impressions of our respondents and challenged pre-existing assumptions. To avoid using leading questions, we used questions open-ended in the respondents' language (Weber et al., 1994; Sacks & Westwood M, 2003). We believe that the relationship between each child and the exercise psychologist is likely to have been advantageous during the interview process. In-depth knowledge of each child facilitated suggestions of concrete examples that he/she could understand in order to explore the intervention topics and to assist the child to express ideas. This was particularly useful when exploring some topics that were difficult to talk about or were too abstract to understand. Knowing the child's reaction in different contexts was very useful.

RESULTS

Categories

In the following section we have condensed the identified themes into categories with the corresponding quotes from the interviews. These categories include four identified themes (physical activity with an ambassador, participation in group training sessions, support from significant others and enabling improvement of current physical and psychological wellbeing) which enable an increase in motivation as well as three identified barriers (poor physical wellbeing, compliance with treatment and limited training facilities) constraining physical activity during cancer treatment. Table 2 shows the categories, interview dimensions and corresponding qualities stated by the children.

Category 1: Ambassadors and group training

The children described how they looked forward to and prepared for visits of their ambassadors. When the ambassadors were present, patients experienced that their desire and level of participation in physical and social activities increased as did participation in normal daily activities (Table 2).

- [It affects] my mood. ... I'm much happier when they're here (male, 8 yrs.).
- That way...we can motivate each other, right? If there's someone here that you really get along with...then you can...do push-ups...". "Come on, darn it! You can do the last one! I just did it." (said in a pressing tone of voice) and this waythey motivate you...or alternatively you can motivate yourself, right? (male, 16 yrs.).
- Yeah, it was definitely more fun and easier to train when my ambassador was with me (male, 9 yrs.).

The children described interactions with peers as being uplifting, more fun and shifting focus away from illness, and generally as creating normality in daily live (Table 2).

- I also think it was really fun at the group training sessions with ambassadors, in particularly those tests. It was actually really fun. For example, we make a contest out of it (male, 14 yrs.).

- Training was cool because...it's always fun to train with others that you get along with...people that you know...just like last time when we trained...it was cool that were able to sit and do those exercises together. I thought that was really cool (female, 8 yrs.).
- ... it's more fun to train with others than doing it alone (male, 14 yrs.).
- At group training, we also had fun and it was a like a common activity where there were many children. Children with cancer and their ambassadors. It's just a good thing. For even if you have cancer, you still think back on it as a good memory and I think it is important to have good memories even though it was an extremely bad year (male, 16 yrs.).
- Was it exhausting to have visits [from the ambassador]? Yes it was... because it takes like a lot of energy to have visitors (male, 14 yrs.).

Group training increased motivation and provided opportunity to engage in games, friendly competition and to receive support from others. Moreover, group training distracted the children and made time pass faster (Table 2).

- Because it [training] makes the day pass faster. The major focus when you have cancer is to get rid of it right away...and fast! You don't feel like experiencing long boring days and feeling bad (male, 14 yrs.).
- ... it was pretty fun to see how well they did [the ambassadors during training sessions] and how much [physical capacity] I had lost because of treatment. It was a bit funny, but also annoying. I was the strongest in class before and now I was suddenly the weakest one (male, 12 yrs.).
- Do you remember whether you thought it was a good idea [to do exercise] in the beginning? When you feel the way I did ... I was, I was a bit annoyed because I felt so bad (female, 13 yrs.).

Category 2: Significant others and daily routines and habits

The children explained that the diagnosis and inpatient treatment disrupted everyday life. They struggled to understand their new reality and to establish new daily routines. This was further complicated because they had to alternate between hospital and home settings erratically. Individualized training offered each child a daily activity routine. Parents also have a major role influencing the children to participate in the physical training intervention and helping them create new habits and routines.

- Because it wouldn't be the same. I wouldn't be forced like I am when you (the exercise psychologist) come every day. When you're forced to do it, it's easier to get started (male, 14 yrs.).
- I came to your room and wanted you to exercise both on good days and on bad days. Yes. What does it mean? It means a lot. It is good to know you have to exercise every day (male, 12 yrs.).
- That [being forced by the exercise psychologist] was good. When I was told that I had to train, I did it because I had to. Here at home, I constantly think about starting training but I never do (female, 13 yrs.).
- When I [exercise psychologist] came to your room and said; 'Get out of the bed, you must exercise'. What did you think about that? I thought; Oh no, oh no, here he comes again. What is it, we have to do now? Would you rather if I didn't come? No (male, 8 yrs.).
- My dad does [decides when I should train]. Sometimes when I didn't really feel like it, my Dad would say that I had to do it anyway (female, 8 yrs.).
- My mother did [decide when I should train]. Yeah, she decides just about everything (male, 9 yrs.).
- It's easier when you are dragged out of bed [by the exercise psychologist] and told, 'Now, get going' (female, 16 yrs.).
- Sometimes, it was very annoying. I woke up, took my medicine and then my mother said you've [exercise psychologist] been here and I should exercise. But, NO, I will not! I'll have

my breakfast and then I'll just want to be left in peace for the rest of the day. I will not go to school and I do not want to do anything (male, 14 yrs.).

The daily training sessions and interaction with the exercise psychologist helped them gain knowledge about physical activity during treatment, complying with the treatment regimen and dealing with severe side effects (Table 2).

- Yeah, and it turned out to be a good thing anyway... Yeah, [it's because] you don't have the strength... you are tired or not feeling well enough but when you are pushed to do it, it turns out to be okay anyway. That's because you're just happy to be able to train. At least that's how I see it. So, it's always nice to be able to train even when you don't feel up to it at the beginning (female, 16 yrs.).
- Firstly, because you don't feel like it and then because you forget exactly what you have to do. You don't really know the exact things [exercises] you are supposed to do and that makes you not want to even try (female, 13 yrs.).
- That was very funny, actually. I certainly gained much from it. I think it was interesting to see that you could actually improve [your physical wellbeing, fitness] during cancer treatment (male, 16 yrs.).

Individualized training offered positive perspectives such as regaining control of own physical condition and life following treatment (Table 2).

- I think...that it was a great idea to have...individualized training because sometimes there's a need for it instead of group training. It allows ... much more focus on self than on all the others as well (male, 14 yrs.).

The amount of knowledge, resources and support from their parents varied during therapy (Table 2).

Category 3: Wellbeing

Physical and psychological wellbeing was affected by side effects and treatment complications rapidly changing throughout the course of treatment. Following training sessions the children

described feeling naturally tired and cheerful having accomplished something as well as feeling normal, active and satisfied (Table 2).

- I feel happy but also really tired. Your legs hurt the next day... Well, you feel happy that you could do it... that you did something that day...that you can still do something physical (female, 13 yrs.).
- Well, you feel revitalised; really alive and it's as though you have more energy (male, 16 yrs.).
- Was it tough [doing exercise]? Yes, it was tough (male, 8 yrs.).
- [if you were already feeling unwell, did it [training] make you feel worse or unable to sleep?] No, it made me feel better. I felt better afterwards (female, 16 yrs.)
- Because once you actually start training...you begin to think...about all the good it's doing and you feel happier and forget about that medicine you were given that makes you so bad... I think that training puts you in a better mood... (male, 12 yrs.)
- ... it makes you feel better about yourself. You feel the world is more fun (male, 12 yrs.).
- ... still, you could keep up your spirit when you do exercises I think you get in a better mood when doing physical training (female, 13 yrs.).
- Just the fact that you're doing something instead of just lying there....and you feel a little happier afterwards. That's always good. I think that's the best thing about it. And you don't feel weaker and weaker but [rather] that you're trying to keep a certain level of fitness for your muscles and stuff (female, 16 yrs.).

Following training sessions the children described feeling more empowered – 'Does training sessions affect your self confidence in any way?'

- Yeah, because you feel that you're getting a little bit better in dealing with things (male, 14 yrs.).

Category 4: Treatment compliance and training facilities

The children described the paediatric oncology wards' physical environment as not being supportive for physical activity. This led to decreased motivation to do exercise (Table 2).

- It felt a bit claustrophobic [doing exercise in the room]. But still it was fun. And even so, you were able to keep your spirits up and train (male, 12 yrs.).
- ...it's not so motivating doing exercise in your room (male, 16 yrs.).

The children described that group training held in the physiotherapy department, its spaciousness and its equipment as motivating for physical activity.

- Yeah, I think so. Because you feel once again like you're not always at the hospital if you go to the gym or other places (male, 16 years).
- I think that's really cool. I really mean it. And then there's the fact that you get a break from your parents, especially when you're a teenager...when you're trying to separate yourself a bit from them...but then all of a sudden you're shoved back into that little room with them again. It's really great to be able to get out of bed and move around a little and not just lie belly up staring at the ceiling. It's cool...socially I really like it (male, 16 yrs.).

In contrast, treatment equipment was barriers obstructing physical activity (Table 2).

- I remember going on a few walks even though I had to do it with a drip stand. And I felt that it was totally unfair because it was so boring walking up and down the hospital corridors... especially with that drip-stand. Walking back and forth is so boring (male, 14 yrs.).

A new relevant finding emerged, which we labelled '*hidden* physical activity'. Children do not perceive daily activities, such as cycling to school, climbing stairs, get into and out of a chair and walking around as being physical activity. When asked if they performed any daily physical activities during therapy they responded by reflecting on their pre-diagnosis experience with, for example sports, indicating that their perception of physical activity was restricted to such defined context and setting.

DISCUSSION AND PERSPECTIVES

This study shows that it is possible to motivate children to be physically active during treatment despite a severe decline in physical fitness, multiple treatment side effects and the non-conducive facilities for physical activity within the hospital setting. All children included in the RESPECT intervention (N=75) participated in the physical activity sessions, confirming the components as being appropriate and well established. There were no drop-outs from the intervention program.

The qualitative analysis showed that the children's motivation for engaging in physical activity during intensive treatment was influenced primarily by 1) opportunity for physical activity with an ambassador; 2) participation in group training sessions with other children with cancer and their ambassadors; 3) support from significant others; and 4) enabling improvement of current physical and psychological wellbeing. The significant others (Sullivan, 1953) in this confined hospital setting are primarily their parents and the exercise psychologist. Main barriers included 1) poor physical wellbeing (for example cancer symptoms; side effects to treatment), 2) compliance with treatment, medical procedures and being treated in protective isolation; and 3) limited training facilities in the paediatric oncology ward (Table 2).

Frequency and compliance mainly differed depending on diagnosis, in-patient days and level of side effects. It is important to understand the premise and setting underlying the intervention. Even on a 'good day' it was very difficult to activate and exercise the children at the oncology ward. Very few children exercised satisfactory on their own, partly due to their lack of knowledge about exercise during treatment, and partly because of the challenges children with cancer face on a daily basis, such as severe side effects, treatment compliance and generally low levels of energy. On a daily basis a form of negotiation took place between the child with cancer and the exercise psychologist trying to motivate the child to exercise. This negotiation considered each child's needs and daily physical and mental condition as well as capabilities and based on this 'negotiation' a specific exercise session was agreed upon. When the child with cancer was not able to perform physical exercise, social and/or mental skills training were performed. Sometimes the children with cancer were not able to perform any exercise at all and no training was attained.

Psychosocial support

We found that the children's primary motivational factor for doing physical activity was presence of their healthy classmate ambassadors (Table 2). Every child mentioned the benefits and motivations derived from visits by their classmates. The ambassador's act as a bridge between the children's everyday lives at home and at the hospital, and serve as role models. Furthermore, the ambassador provides moral support, familiarity, and encouragement, and helps to create a friendly educational, physical, and social environment for the child with cancer (Table 2). Classmate visits promoted normalcy and daily life, even within the hospital setting (Table 2). The ambassadors performed the activity with the patients, thus promoting scheduled and improvised physical activity. Being with other children during an exercise session provided healthy peer pressure and an opportunity to surpass own expectations and compete against others (Table 2) — all factors resembling normal everyday life. The children described their healthy classmates as bringing energy and fun to interactions, motivating them to be active. Hence, the presence of ambassadors promoted the children's level of physical activity and secondary socialization. During the intervention study we have seen that it is possible to allocate ambassadors for all children and that the ambassadors were highly motivated for providing in-hospital patient support during childhood cancer therapy (Lindgren, Schmiegelow, Helms, Thorsteinsson, & Larsen, 2016; Baekgaard H, Helms AS, Thorsteinsson T, Simovska V, Schmiegelow K, 2017 (submitted)).

Professional support

Children describe the need to be supported continuously and gain knowledge on how and what to do in their current situation (Table 2). They describe the difficulty in doing it on their own (Table 2). The level of support from parents and professionals influence the children's level of motivation for physical activity (Table 2, Gilliam et al., 2013). This makes professional support pivotal (Jarden et al., 2013). We wanted to create a professional relationship with each child and their family, building trust and confidentiality by continuity and professional support; accordingly we visited every child in the oncology ward on a daily basis. It requires flexibility and an individual approach to work in such an unusual setting with different types of children and families. We wanted to empower the children and their families and invited them to be curious and try to learn how to cope and actively participate in their own rehabilitation and gain an educational effect of the intervention program. We did this by continuously addressing health issues, both physical, social and psychological and overall tried to empower the children and their families to be active, in the sense of doing physical and mental exercises, reinforcing own support systems and by retrieving and sharing knowledge to better

understand and break the taboo of serious illness. In this way we hope the children and their families will feel more empowered after cessation of treatment and less as a victim. The professional support should be targeted at both the children and their parents. It is essential with an individualized approach to better understand the child's resources and preferences for physical activity. Performing physical activity when hospitalized is challenged by compulsory adherence to treatment protocols as well as treatment side effects and complications. It is not very motivating to do physical with various medical devices attached to your body (e.g. a drip stand, Central Venous Catheter or a Patient-Controlled Analgesia pump) (Table 2). Intensive cancer treatment often results in the child's wellbeing fluctuating from one minute to the next. As such, physical activity sessions need to be flexible and planned on a day-to-day basis.

Pre-diagnosis level of physical activity and facilities

The children associated their physical activity with regular activities pre-diagnosis. However, the children do not consider daily life activities such as walking or cycling as physical activity. Nonetheless, due to the decreased physical fitness of these children, those simple activities were equivalent to moderate to intense physical training. Thus, regular everyday physical exercise, such as cycling to school, constitutes physical activity with positive effects in healthy children (Ostergaard, Borrestad, Tarp, & Andersen, 2012). It is important to identify 'hidden' activity when monitoring each child's level of physical activity during treatment. This is a relevant finding, partly in relation to interviewing children and partly in relation to creating a relevant and tailored physical exercise intervention with children with significantly reduced physical capacity and function.

There is a need to rethink how to furnish hospital rooms, corridors and common spaces to be motivational for undertaking physical activity (Table 2). Studies, including the current one, show that facilities for physical activity are important for promoting and motivating children to be physically active (Nielsen, Bugge, Hermansen, Svensson, Andersen, 2012).

CONCLUSION

Despite barriers, it is possible to motivate children with cancer to become physically active during intensive chemotherapeutic treatment in a paediatric oncology ward. Support from ambassadors, parents and professionals are predictors of the child's motivational level. Physical exercise and activity should be recommended and promoted from diagnosis throughout the treatment period including psychosocial and professional support.

ETHICAL APPROVAL

Information on the study subjects is protected under the Processing of Personal Data and Health Act. The Danish Data Protection Agency (file. 2007-58-0015/nr.30-0734) and the Regional Ethics Committee for the Capital Region (file. H 3-2012-105) approved the project, and the project complies with the Helsinki II Declaration. In addition, the study is registered at Clinical Trials.gov (NCT01772849 and NCT01772862). Following receipt of oral and written information, parental, guardian and the child's (children above 15 year) written informed consent was obtained.

COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHORS' CONTRIBUTIONS

KS and HBL designed the study. KS is the study's Scientific Director, and HBL is the main Project Coordinator of the RESPECT project. TT drafted the first version of the manuscript and is responsible for the physical and social activity intervention together with LBO and LFT. ASH is responsible for the educational intervention of the RESPECT study. LHL has been involved in the analysis and the transcripts of the interviews. All authors contributed to revision of the written manuscript and read and approved the final manuscript and completed the ICMJE uniform disclosure form.

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REFERENCE LIST

- Baekgaard H, Helms AS, Thorsteinsson T, Simovska V, Schmiegelow K. Feasibility of classmates as ambassadors for children with cancer as facilitators of social-, physical- and educational rehabilitation activities in the RESPECT study. (Submitted)
- Barakat LP, Galtieri LR, Szalda D, Schwartz LA. Assessing the psychosocial needs and program preferences of adolescents and young adults with cancer. *Support Care Cancer*. 2016 Feb;24(2):823-32. doi: 10.1007/s00520-015-2849-8. Epub 2015 Jul 21.
- Braam KI, van der Torre P, Takken T, Veening MA, van Dulmen-den Broeder E, Kaspers GJ. Physical exercise training interventions for children and young adults during and after treatment for childhood cancer. *Cochrane Database Syst Rev*. 2016 Mar 31;3:CD008796. doi: 10.1002/14651858.CD008796.pub3.
- Brown PD, Olsen JH, Hertz H, Carstensen B, Bautz A. [Survival after childhood cancer in Denmark 1943-1987. A population-based study]. *Ugeskr Laeger* 1996 Feb 5;158(6):773-8.
- DuHamel KN, Redd WH, Vickberg SM. Behavioral interventions in the diagnosis, treatment and rehabilitation of children with cancer. *Acta Oncol* 1999;38(6):719-34.
- Gatta G, Zigon G, Capocaccia R, Coebergh JW, Desandes E, Kaatsch P, Pastore G, Peris-Bonet R, Stiller CA. Survival of European children and young adults with cancer diagnosed 1995-2002. *Eur J Cancer* 2009 Apr;45(6):992-1005.
- Giddens A SPW. *SOCIOLOGY*. 7th edition ed. Polity Press; 2013. p. 332-79.
- Gilliam MB, Madan-Swain A, Whelan K, Tucker DC, Demark-Wahnefried W, Schwebel DC. Cognitive influences as mediators of family and peer support for paediatric cancer survivors' physical activity. *Psychooncology* 2013 Jun;22(6):1361-8.
- Grimshaw SL, Taylor NF, Shields N. The Feasibility of Physical Activity Interventions During the Intense Treatment Phase for Children and Adolescents with Cancer: A Systematic Review. *Pediatr Blood Cancer*. 2016 Sep;63(9):1586-93. doi: 10.1002/pbc.26010. Epub 2016 May 17.

- Götte M, Kesting S, Winter C, Rosenbaum D, Boos J. Experience of barriers and motivations for physical activities and exercise during treatment of paediatric patients with cancer. *Pediatr Blood Cancer* 2014 Sep;61(9):1632-7.
- Gurney JG, Krull KR, Kadan-Lottick N, Nicholson HS, Nathan PC, Zebrack B, Tersak JM, Ness KK. Social outcomes in the Childhood Cancer Survivor Study cohort. *J Clin Oncol* 2009 May 10;27(14):2390-5.
- Hartman A, te Winkel ML, van Beek RD, de Muinck Keizer-Schrama SM, Kemper HC, Hop WC, van den Heuvel-Eibrink MM, Pieters R. A randomized trial investigating an exercise program to prevent reduction of bone mineral density and impairment of motor performance during treatment for childhood acute lymphoblastic leukemia. *Pediatr Blood Cancer*. 2009 Jul;53(1):64-71. doi: 10.1002/pbc.21942.
- Huang TT, Ness KK. Exercise interventions in children with cancer: a review. *Int J Pediatr* 2011;2011:461512.
- Jarden M, Adamsen L, Kjeldsen L, Birgens H, Tolver A, Christensen JF, Stensen M, Sørensen VA, Møller T. The emerging role of exercise and health counseling in patients with acute leukemia undergoing chemotherapy during outpatient management. *Leuk Res* 2013 Feb;37(2):155-61.
- Jones LW, Liu Q, Armstrong GT, Ness KK, Yasui Y, Devine K, Tonorezos E, Soares-Miranda L, Sklar CA, Douglas PS, Robison LL, Oeffinger KC. Exercise and risk of major cardiovascular events in adult survivors of childhood hodgkin lymphoma: a report from the childhood cancer survivor study. *J Clin Oncol* 2014 Nov 10;32(32):3643-50.
- Keats MR, Culos-Reed SN, Courneya KS, McBride M. Understanding physical activity in adolescent cancer survivors: an application of the theory of planned behavior. *Psychooncology*. 2007 May;16(5):448-57.
- Lindgren LH, Schmiegelow K, Helms S, Thorsteinsson T, Larsen HB. In Sickness and in Health: Classmates are Highly Motivated for Providing In-hospital Patient Support during Childhood Cancer Therapy. *Psycho-Oncology* 2016. Vol 26, 1:37–43

- Lund LW, Schmiegelow K, Rechnitzer C, Johansen C. A systematic review of studies on psychosocial late effects of childhood cancer: structures of society and methodological pitfalls may challenge the conclusions. *Pediatr Blood Cancer* 2011 Apr;56(4):532-43.
- Malterud K. Systematic text condensation: a strategy for qualitative analysis. *Scand J Public Health*. 2012 Dec;40(8):795-805. doi: 10.1177/1403494812465030
- Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet* 2001 Aug 11; 358(9280): 483-8.
- Mitby PA, Robison LL, Whitton JA, Zevon MA, Gibbs IC, Tersak JM, Meadows AT, Stovall M, Zeltzer LK, Mertens AC. Utilization of special education services and educational attainment among long-term survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Cancer* 2003 Feb 15;97(4):1115-26.
- Nielsen G, Bugge A, Hermansen B, Svensson J, Andersen LB. School playground facilities as a determinant of children's daily activity: a cross-sectional study of Danish primary school children. *J Phys Act Health* 2012 Jan;9(1):104-14.
- NVivo qualitative analysis software [computer program]. Version 10 QSR International Pty Ltd.; 2012.
- Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows AT, Friedman DL, Marina N, Hobbie W, Kadan-Lottick NS, Scharrtz CL, Leisenring W, Robison LL. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med* 2006 Oct 12;355(15):1572-82.
- Ostergaard L, Borrestad LA, Tarp J, Andersen LB. Bicycling to school improves the cardiometabolic risk factor profile: a randomised controlled trial. *BMJ Open* 2012;2(6).
- Sacks D, Westwood M. An approach to interviewing adolescents. *Paediatr Child Health* 2003; 8: 554-556.
- Smith MA, Seibel NL, Altekruse SF, Ries LA, Melbert DL, O'Leary M, Smith FO, Reaman GH. Outcomes for children and adolescents with cancer: challenges for the twenty-first century. *J Clin Oncol* 2010 May 20;28(15):2625-34.

Sullivan HS. *THE INTERPERSONAL THEORY OF PSYCHIATRY*. 1st edition ed. New York : Norton; 1953.

Tai E, Buchanan N, Townsend J, Fairley T, Moore A, Richardson LC. Health status of adolescent and young adult cancer survivors. *Cancer* 2012 Oct 1;118(19):4884-91.

Thorsteinsson T, Helms AS, Adamsen L, Andersen LB, Andersen KV, Christensen KB, Hasle H, Heilmann C, Hejgaard N, Johansen C, Madsen M, Madsen SA, Simovska V, Strange B, Thing LF, Wehner PS, Schmiegelow K, Larsen HB. Study protocol: Rehabilitation including Social and Physical activity and Education in Children and Teenagers with Cancer (RESPECT). *BMC Cancer* 2013;13:544.

Weber L, Miracle A, Skehan T. Interviewing early adolescents: some methodological considerations. *Human Organization* 1994; 53: 42-47.

Winter C, Muller C, Hoffmann C, Boos J, Rosenbaum D. Physical activity and childhood cancer. *Pediatr Blood Cancer* 2010 Apr;54(4):501-10.

World Health Organisation (WHO) - *GLOBAL RECOMMENDATIONS ON PHYSICAL ACTIVITY FOR HEALTH*. 2010. Ref Type: Internet Communication

TABLES

Table 1a Characteristics of the intervention cohort and interview information. Data on cancer diagnosis and date of diagnosis were collected from medical records.

Gender	Age	Diagnosis	Ethnicity	Time - diagnosis to interview (days)	Duration of interview (min.)
Female	8	ALL	Danish	342	44
Male	8	ALL	Danish	235	41
Male	9	Lymphoma	Middle eastern	207	25
Female	9	ALL	Danish	450	40
Male	12	LCH	Danish	165	30
Male	12	Lymphoma	Danish	146	62
Female	13	ALL	Middle eastern	395	61
Female	13	Lymphoma	Danish	175	53
Male	14	AML	Danish	328	90
Male	14	ALL	Danish	252	26
Female	15	CNS	Danish	286	30
Male	16	Solid tumour	Danish	256	47
Female	16	Solid tumour	Danish	377	63

Abbreviations: ALL = acute lymphoblastic leukaemia, AML = Acute myeloid leukaemia, LCH = Langerhans Cell Histiocytosis, CNS = central nervous system.

Table 1b Levels of participation in the training scheme and physical activity pre-diagnosis collected at diagnosis.

Inpatient days - diagnosis to interview**	Individual training sessions	Group training sessions	Prior physical activity level*
86	46	11	Active
133	53	15	Not active
83	44	8	Not active
117	59	10	Not active
8	8	16	Not active
87	53	20	Active
99	41	8	Not active
15	11	2	Active
193	73	23	Active
122	68	15	Active
59	24	3	Not active
52	37	3	Active

175	67	16	Not active
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*Active is defined as a least 60 min. activity 3 times weekly (World Health Organisation (WHO) 2010).

**Cumulative days of admission with outpatient time in between.

Table 2 Categories, interview dimensions and corresponding qualities stated by the children.

Categories	Dimensions	Qualities
1. Ambassadors and Group training	Group training	Competing with others Healthy peer pressure Proving oneself Surpassing expectations
	Psychological	Lifting spirits Change in focus (away from illness) More fun Time flies More daring
2. Support from significant other and daily routines and habits	Individual physical training scheme / intervention setting	Getting it done Healthy pressure New knowledge New/good habits Competing against self
	Parents	Social support Empowerment Meaningfulness Authority
3. Wellbeing	Physical wellbeing	Side effects Sleep efficacy
	Psychological wellbeing	Lifting spirits Accomplishing something Feeling satisfaction Normality Feeling active Fighting cancer
	Limitations	Side effects Cancer type (e.g. brain tumour or solid tumour) Wake-up call Physical wellbeing
4. Treatment compliance and facilities	Organizational limitations	Obstructed by chemo (drop stand and/or regulations) Examinations Safety
	At the paediatric oncology ward	Less fun Fewer games Less playfulness
	In the gym	More fun More games More playfulness

SUPPLEMENTARY FILE

Supplementary file 1 Exercise Library: Overview of exercises primarily used in the physical training programme. The focus was on stability/balance, mobility, strength (resistance) and cardiorespiratory fitness. Several of the exercises affect more than one focus area.

Mobility, strength
Lower-extremity exercises:
Up on toes / walk on toes
Up on heels / walk on heels
Squat (air, front, Bulgarian)
Wall sit
Deadlift (both legs, single leg)
Thrusters
Lunges
Side step / shuffle
Side step / shuffle crossover
Skip
Walking backwards
Jumps
Jumping jacks
Frog jumps
Knees to elbows
Crawl (bear, crab)
Making turns
Upper-extremity exercises:
Push-ups
Fly
Rowing
Shoulder press
Flyers
Laterals
Dips
Dumbbell press
Pull-down
Bicep curl
Hammer curl
Push-down
Core and pelvis exercises:
Hip thruster
Plank

Back extensions
Abdominal crunch / sit-up
Leg lifts
Bicycle legs
Stability/balance and cardiorespiratory fitness
Balance, stability and neuromuscular exercises:
Stand on one leg
Walk in a straight line
Agility course
Balance on an unstable base (e.g. foam pad)
Balance board
‘Throwing’ balls from unstable surfaces
Sitting and kneeling balance exercises on Swiss exercise ball (eyes open and closed)
Cardiorespiratory fitness exercises:
Steps
Bicycle ergometer
Treadmill
Cross trainer
Running / marching on the spot
Walks
Walking in intervals
High knee running
Step up onto bench
Heel kick running
Stairways
Play/games
The floor is made of lava
Playing with balls (variations of throws and kicks)
Game of tag
Agility course
Kings successor
Interactive screen
Silly walks
Hopscotch
Minor training programmes
7-min workout
Superheroes workout

Figure 1

The Pediatric Exercise Model combines the children's motivation for being physically active with the level of support they receive from their parents during treatment from a motivational point of view.

1	2
+ Active before diagnosis + Support from significant other ↓ High level of motivation and activity	- Not active before diagnosis + Support from significant other ↓ High/medium level of motivation and activity
3	4
+ Active before diagnosis - No support from significant other ↓ Medium/low level of motivation and activity	- Not active before diagnosis - No support from significant other ↓ Low level of motivation and sedentary activity